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ABSTRACT

This brochure argues for consistency in how disabilities are named in national data collection programs. It notes that currently many students with disabilities are excluded from national data collection programs and, when they are included, there is extreme variability in the disability classification assigned to them. Nineteen different national data collection programs were examined, of which only 10 identified students with a learning disability. A table lists each of the data sources and the special education categories recognized. It is recommended that the federal government and researchers: (1) develop a more uniform, perhaps standardized, system for naming disability conditions, possibly paralleling the federal special education categories; (2) initiate a dialogue among representatives from the appropriate federal groups and agencies, both educational and non-educational to identify possible means for collecting uniform disability-related data across agencies, especially for the school age population; (3) alternatively, develop "cross-walk" procedures to allow agencies' disability category systems to be converted to the federal special education system; and (4) intensify efforts to include all students and individuals with disabilities in national data collection programs and develop guidelines in testing accommodations. (DB)

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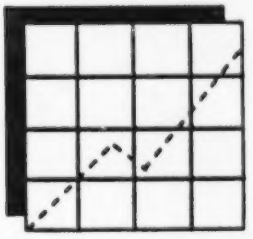
ED 373 505

Consistency Needed in Naming Disabilities in Data Collection Programs



BRIEF REPORT
10

National Center on Educational Outcomes

EC 303274

May, 1994

Consistency Needed in Naming Disabilities in Data Collection Programs

Many national data collection programs are potentially rich sources of information on important outcomes for students with disabilities. However, as currently designed, it is impossible to get at this rich source of information and use it in the development of policy for students with disabilities. There are two main reasons:

1. **Many students with disabilities are excluded from national data collection programs.**

2. **When they are included, there is extreme variability in the disability classification that is assigned to them.**

These two points illustrate the lack of communication among national data collection programs on disability-related issues. Unfortunately, it means that there are major gaps on what is known about students and adults with disabilities, and the effectiveness of institutions in working toward meeting their needs.

This topic is extremely timely, given that approximately 4.8 million school-age youngsters with disabilities receive some form of special education services—services that are provided at significant expense to our educational system. Not being able to document the effectiveness of the services provided to them and the outcomes of adults who received special education services is potentially very costly.

In order to learn more about where the gaps exist, NCEO examined the ways in which groups of students are identified by national data collection programs. In the nineteen national data collection programs examined, only ten identified students with a learning disability, the

category of approximately 2.4 million students. The programs studied were eleven programs from the Department of Education, five from the Department of Health and Human Services, and others from the National Science Foundation, Department of Commerce, and Department of Justice. As is evident in the table on the next page, variability in classification exists within and between these governmental departments.

Lost Opportunities

Exclusion of individuals with disabilities is a major concern. Policies that affect individuals with disabilities often are set without the advantage of relevant information because members of the disability community are not represented in assessments.

Although some of the non-educational data collection programs do not gather any disability-related information, others do, but use a different conceptual framework. The categories that are used often do not correspond to the federal special education disability categories.

Given that many of these non-educational data collection programs are some of the most inclusive national programs in terms of individuals with disabilities, the lack of any disability-related category variables, and the limited correspondence that exists results in a significant "lost opportunity" for the production of important policy-relevant information on this significant portion of the population.

Another lost opportunity results when data collection programs allow for the identification of individuals with disabilities, but the data are never analyzed with respect to disability or disability category. These opportunities need not be lost. Turn to page seven for a set of recommendations to avoid lost opportunities.

Select Category Names Used in Select National Data Collection Programs *

Data Source/Agency	Federal Special Education Category **			
	LD	SED	MR	SI
BB93/Department of Education	•			•
BPS 90/Department of Education	•			•
CPS/Department of Commerce				
LSAY/National Science Foundation				
NAEP 88/Department of Education	•	•	•	•
NALS 92/Department of Education	•	•	•	•
NASHS 88/Dept of Hlth & Human Servs				
NCS 86-89/Department of Justice				
NELS 88/Department of Education	• •			
NHEFS 86/Dept of Hlth & Human Servs				
NHES 91/Department of Education				
NHESC 91/Department of Education	•	•	•	•
NHIS 89/Dept of Health & Human Servs		• • •	•	• •
NLTS 87/Department of Education	•	•	•	•
NSFG 88/Dept of Health & Human Servs				
TS 87/Department of Education	•	•	•	•
TSAP 90/Department of Education	•	•	•	•
YALS 85/Department of Education	•			•
YRBS90-91/Dept of Hlth & Human Servs				

*Table entries represent the number of category terms used in the national data source that correspond to the federal special education category (e.g., NHIS has two categories of speech impairment — (1) stammering/stuttering, and (2) other speech impairment). The entry ••• indicates 3 or more categories are used for the one federal category. Shaded cells indicate that no categories correspond to the federal special education category.

**Federal categories are as follows:
LD = learning disability
SED = serious emotional disorder
MR = mental retardation
SI = speech impairment

Data Sources

BB93 = Baccalaureate and Beyond Longitudinal Study
BPS90 = Beginning Postsecondary Student Longitudinal Study
CPS = Current Population Survey
LSAY = Longitudinal Study of American Youth
NAEP88 = National Assessment of Educational Progress
NALS92 = National Adult Literacy Survey
NASHS88 = National Adolescent Student Health Survey
NCS86-89 = National Crime Survey
NELS88 = National Education Longitudinal Study of 1988
NHEFS86 = National Health and Nutrition Examination Survey, Epidemiologic Follow-up Study
NHES91 = National Household Education Survey (Adult Version)
NHESC91 = National Household Education Survey (Child Version)
NHIS89 = National Health Interview Survey
NLTS87 = National Longitudinal Transition Study of Special Education Students
NSFG = National Survey of Family Growth
TS87 = 1987 Transcript Study
TSAP90 = National Assessment of Educational Progress, Trial State Assessment Program
YALS85 = Young Adult Literacy Survey
YRBS90-91 = Youth Risk Behavior Survey

Additional information on these data sources is provided in NCEO Technical Report 6 (McGrew, Algozzine, Spiegel, Thurlow, & Ysseldyke, 1993, *The Identification of People with Disabilities in National Databases: A Failure to Communicate).*

Recommendations

- We need a more uniform, perhaps standardized, system for naming disability conditions. A system that parallels the federal special education categories should be used.
- A dialogue should be initiated between representatives from the appropriate federal groups and agencies, both educational and non-educational, to identify possible means by which uniform disability-related variables could be collected across agencies, particularly for the school-age portion of each data collection program.
- Alternatively, the feasibility of developing "cross-walk" procedures that would allow the different agencies' disability category system to be converted to the federal special education system should be studied.
- Continued efforts in including all students and individuals with disabilities in national data collection programs and developing guidelines in testing accommodations will improve the quality of data on this population.

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The National Center on Educational Outcomes (NCEO) was established in October, 1990 to work with state departments of education, national policy-making groups, and others to facilitate and enrich the development and use of indicators of educational outcomes for students with disabilities. The Center represents a collaborative effort of the University of Minnesota, the National Association of State Directors of Special Education, and St. Cloud State University. The Center is supported through a Cooperative Agreement with the U.S. Department of Education, Office of Special Education Programs (H159C00004). Opinions or points of view do not necessarily represent those of the U.S. Department of Education or Offices within it.

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